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ABSTRACT

This site visit report describes activities, strengths, and challenges of the Area Agency for Developmental Services in Region VI of New Hampshire, with an emphasis on bringing people with developmental disabilities out of the state institution to community-based services. The agency provides case management services, family support services, and residential services to approximately 400 people. Case management is intended to prevent "dumping" of people from the state institution into the community without services or support. Case management involves developing Individualized Service Plans, being on call, serving as advocates, and helping people obtain benefits for which they qualify. The family support service component involves coordinating the Family Support Advisory Council, serving as a family liaison resource, linking clients to recreational opportunities, encouraging parent networking, and providing respite services. Development of residential services involves deinstitutionalization, development of individualized supports, planning, and accessing community resources for appropriate housing. The agency's quality assurance program stresses frequent evaluations and community presence, individual rights, competence development, status improvement, and community participation. (DB)

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COMING HOME: FROM DEINSTITUTIONALIZATION TO SUPPORTING PEOPLE IN THEIR OWN HOMES IN REGION VI, NEW HAMPSHIRE

Center on Human Policy

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Coming Home: From Deinstitutionalization to Supporting People in Their Own Homes in Region VI, New Hampshire

by

Pam Walker

March 1993

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Coming Home: From Deinstitutionalization to Supporting People in Their Own Homes in Region VI, New Hampshire

Introduction

Throughout the 1980s, the Area Agency for Developmental Services in Region VI of New Hampshire focused much of their efforts on bringing people living at the state institution in Laconia "home" to community-based services. Currently, their work centers on assisting people to live in their own homes, with the supports they need. The experiences described in their paper may be useful to people in other states who are challenged by both institutional closure and, at the same time, creating quality, individiualized supports in the community. This paper is based on a site visit to the area agency in Region VI in September 1991. It reflects the area agency at that point in time, and not any changes which may have occurred since then.

In the early 1980s, the state of New Hampshire was at the same time expanding its community service system for people with developmental disabilities, and working toward closure of its state institution at Laconia, based on a 1981 federal court decision. At this time, based on a state plan, "Action for Independence," the area agency structure was established, creating 12 area agencies for provision of community-based services for people with developmental disabilities.

Each area agency has an area agency board, which makes policy based on the region's needs. Area agencies receive funding from the state; they, in turn, decide how to allocate this funding within their region. All area agencies provide case management. Beyond this, some area agencies provide many services directly, while others contract with vendors, who provid services in the regions.

Region VI encompasses the cities of Nashua and Merrimack, as well as several towns to the east and west. In the past 10-15 years, this region has been increasingly populated by people who commute the 50 miles or so to the metropolitan Boston area for work. The landscape is characterized by suburban sprawl, as space in between the towns and cities is gradually filled in with condos and shopping plazas.

Of the 12 area agencies state-wide, Region VI is the second largest, in terms of number of people served. It has grown from serving 50 people in 1981, with a 0.5 million budget, to serving 400 in 1991, with a budget of 9 million. Besides case management, the Region VI area agency also provides family support services and respite; it contracts with private vendors for other services.

Because of the larger size of this region, there are more vendors for the area agency to choose among than in many other regions. According to the area agency director, Sandra Pelletier, this offers "more flexibility, and creates a healthy competition among vendors." Overall, the area agency contracts with six vendors for its residential services. There are other vendors for

vocational services. This paper, however, focuses on residential and family support services, as well as the case management and quality assurance related to them.

Since its establishment, this area agency's values and practices have been influenced and guided by normalization, or social role valorization. Over the years, their values have been consistent, but their ways of putting these into practice have changed as they have learned from people they support and others around the country who are developing new ways of assisting people with developmental disabilities.

Case Management

Case management, as a service, was initiated in New Hampshire in 1979 in order to help prevent the "dumping" of people from Laconia into the community without services or support. In Region VI, case loads are approximately 25, which has included, until the recent closure of Laconia, case loads comprised of some people who lived in the institution and some who lived in the community.

One of the primary components of the case managers' job is to monitor the vendors and the services that are provided to individuals. One case mangager indicated that they visit people on their case loads "at least once a month, but we have lots of other phone contacts with them or with others involved with them." Another major part of their job is convening the Individualized Service Plan (ISP) process, and the annual meeting for this. Every

month they get progress reports from the residential and vocational vendors regarding ISP objectives.

While most of the case managers have a case load of adults who live in various settings (apartments, group homes, parents' homes), a few of them have case loads composed of people with certain common needs. For instance, one case manager focuses on high school age students. She assists the students, their parents, and others in planning for future vocational and residential supports. Another case manager focuses on adults who live with their parents or on their own, whom she characterizes as "survivors" because of their resiliance in the face of needs for things such as food, clothing, and shelter. She assists them in obtaining these things, as well as in making connections with other community members and resources.

There are a number of positive efforts being made by case management staff in Region VI. Some of these are highlighted below.

1. The case managers recognize that there are some people whom they support who dislike having an ISP meeting. As an alternative, they are starting to do what they call "Action Plans," where just the case manager and the person with a disability (and any other individuals whom the person wishes to invite) sit down together to plan. The state has encouraged such creative endeavors on the part of the area agencies. However, a barrier to this is that people whose supports are funded through Medicaid are still required to have an ISP meeting.

2. Case management staff have a commitment to be available to people whenever they are needed, and at the same time to see that people's support systems are expanded. The case management staff have a beeper that they take turns wearing for a week at a time, so that one of them is always on call in case of emergencies. They also mentioned that the director is always available to be called in an emergency. One of their recent efforts has been to develop back-up supports within the vendor organizations. As one case manager explained: "Case managers would get called about all sorts of things, including such things as what to do if someone was refusing to make their lunch for work the next day. Now, the calls they get are more often to inform them on an issue or problems and how it was dealt with."

3. The case managers see themselves as advocates for the person with a disability in instances of disagreement or conflict with vendors and/or the person's parents. The case managers appreciate having a variety of vendors to choose from and work with. Overall, they feel their working relationship with vendors is positive, and that the "vendors seem less competitive with each other than they used to be." Case managers struggle with decisions about when to change vendors--that is, how much to work with one vendor to improve, or how to determine if a change to another vendor will make things better. In the end, decisions about this are made based on the person's and his/her parents' wishes, the case manager's personal judgment, and consultation with other case management staff. If there is a change of vendors, it is positive

that, within the state, there is a fee-for-service payment mechanism, which enables money to move with the person.

In cases of conflict of interest between an adult with disabilities and his or her parents, the case managers see themselves as representing the person with a disability. At the same time, they try to establish and maintain good relationships with parents. They feel that their "good rapport" with parents has helped them through many situations of potential conflict. However, they are also willing to go to court for people's right. Recently, they did so on behalf of a woman whose parents had legal guardianship over her. They were successful in convincing the court to at least limit the parental guardianship to medical issues.

4. A recent initiative was for the case management staff to redefine the job of one of the case managers to that of a "benefits technician." This person focuses on helping people maintain the maximum benefits possible as the agency service settings and supports change. This has been particularly helpful with the changeover to more individualized living arrangements and supported employment.

5. Another initiative has been their efforts to assist people who have developmental disabilities and mental health labels residing in mental health institutions. To this end, as a staff, they are making efforts to develop connections with staff in the mental health system.

All of the above efforts reflect a case management staff that is adapting to the changing needs of people as they move to new settings and are supported in new ways in the community. In this context, their overall focus is both to increase the communication and collaboration between various service providers and others involved in a person's life, as well as to increase the person's connections and supports within the community.

Finally, case managers mentioned that the state is considering expanding the eligibility for developmental disability services to include people with such labels as traumatic brain injury, cleft palate, and attention deficit disorder. They are concerned that this move will overwhelm the system, both in terms of number of people and expertise.

Family Support Services

Family support began in this region in 1984, primarily as respite. Then, in 1989, the region was selected as one of two regions state-wide for family support pilot projects. Also, in 1989, state family support legislation was passed, mandating the provision of family support services through the area agencies and the establishment of family support councils within each area agency.

The goals of the family support program include: (1) to address needs of individual and family to enable them to maximize their potential and enrich their lives; (2) to maintain the disabled individual within their natural home by relieving at least

some of the financial burdens and emotional stresses experienced by family members; (3) to prevent costly out-of-home residential placements; and (4) to preserve the development of relationships between the individual and his/her fellow neighbors.

Approximately 200 families receive some type of family support services, and there is no waiting list for this. There are five major components of the family support program in Region VI: the Family Support Advisory Council, a family liaison, a recreational integration effort, a Pilot Parent program, and a respite care program.

Family Support Advisory Council. This council is composed of family members. Its role is to guide policy and practice in family support. This is achieved through obtaining input about services from individuals and families, evaluation, and planning.

Family liaison. The family liaison assists families to: obtain services, through generic community resources and/or specialized service providers (SSI, Medicaid, etc.); advocate for themselves and their family members; and obtain financial assistance for equipment and other family needs. Region VI was the first to initiate this position, and other regions have since done the same.

The amount of financial assistance available to families ranges, generally, from $500-2,000 per year. Once the family has determined what they need, and the agency has determined how much money is available, the family can either purchase the item, or the agency will purchase it for the family. There is additional money

available for a few families who need it. For instance, in 1991, two families received approximately $4,500. As one family support staff member put it, "this allotment means a lot of things to lots of people." People can use it for anything they want, such as air conditioners, family vacations, and the like. In addition, approximately 20 families receive support for children with high levels of medical need through the Katie Beckett Medicaid waiver.

Recreational links. Based on a survey of individuals and families, the Family Support Advisory Council identified recreation as a priority need. They have begun to address this need in a variety of ways: helping obtain camperships at local camps and individual and family memberships at local recreational settings (i.e., health clubs, YMCAs); helping people establish connections and relationships to other individuals or community groups and organizations. In addition, they have compiled a directory of local recreational settings, providing information on accessibility, types of activities that take place, and so forth. The agency does not operate any segregated recreation programs.

Parent-to-Parent program. Through this program, parents network with each other over the phone and in groups, sharing information and experiences, and developing supportive relationships with each other.

Respite. Of the 200 families who receive services, approximately half use respite, all of which is provided in people's homes or in the community. There are 117 respite providers. The family support program staff provide training for

them in things such as first aid and "effective teaching" methods. They have recruited respite providers in all of the towns within the region, through advertising, public speaking, and networking among respite providers.

There are three levels of hourly payment for respite providers, based on the needs of the child--$4.75, $5.50, and $6.50. The respite providers must have renters' or household insurance, but the family support program has some funds to assist with this if needed. The program pays mileage for providers who travel to do respite.

Families can obtain a waiver, which allows them to hire their own respite provider. Also, through a waiver, the respite providers from the area agency can take responsibility for other children in the household, in addition to the child with disabilities.

Respite care can involve more traditional caretaking or babysitting, or it can be oriented more toward expanding a person's recreational or educational opportunities, depending upon the individual's and family's interests.

Residential Services: From Deinstitutionalization to Individualized Supports in the Community

As of September 1991, within the Region there were 112 adults receiving residential services from six vendors, and 72 people on the waiting list for these services. Most people were living in three- or four-person group homes, while six remained in one group

home, and several were in apartments by themselves or with a roommate, with staff support.

Development of residential supports in Region VI can be characterized as falling into two phases: (1) a focus on deinstitutionalization; and (2) a focus on individualized supports and quality of life. Each will be described in turn.

Deinstitutionalization

Over several years, 68 people from Laconia moved back to Region VI. As the director put it, "We did it one person at a time. We let families 'shop' with vendors to see what they wanted and choose..." At the time, however, the options offered were primarily group living situations, rather than more individually tailored supports to assist people to live in their own homes. At the same time, staff from the area agency and its vendors had to work to gather information about people who had been in Laconia. As one staff member put it, "For a lot of people from Laconia, we got the wrong information, or no information. Assessments were lost, or nonexistent." It is notable, however, that in Region VI, as well as the rest of the state, with the closure of Laconia, almost everyone moved into the community, and not into other institutions or large facilities.

During the years of deinstitutionalization, the types of residential services offered in Region VI have changed from use of eight-bedroom group homes, to use of three- and four-bedroom group homes. Now, however, staff in Region VI acknowledge that the move

to three- or four person facilities was a mistake. They feel that perhaps if they had really listened to people at that time, they would not have created these smaller, congregate settings.

Development of Individualized Supports

Now that everyone is out of Laconia, efforts in the Region are more focused on increasing people's quality of life in the community through provision of more individualized supports. This change came about based on listening to people's dissatisfaction with life in group homes, even the smaller ones; observing the problems inherent in the group home model of services; and connecting with others across the country who are also struggling to find different ways of supporting people.

In order to do this, the area agency has pursued a number of options, including: assisting people to rent or purchase an apartment or house and live with live-in paid roommates; assisting people to rent or purchase a house and live with nonpaid roommates (with a reduction in rent/utilities for the roommate in exchange for some support) and additional staff support; assisting people to live on their own, in a rented or purchased house, with drop-in staff support; and assisting people to share someone else's home (a family or single person). Prior to the last few years, these options were used in this Region, but primarily for people with less severe disabilities. The rates for these settings (per person per day) range from $33.37 to $409.48. This highest rate is for a man who moved out of Laconia who is highly self-abusive, and

currently has two staff members with him at all times because of this.

People with a wide range of needs and desires have been assisted to make choices about where they want to live and with whom. For example, Rob and Tim, two brothers with severe and multiple disabilities, share a condominium, with live-in and drop-in staff support. Sarah, who has a label of mild mental retardation and uses a wheelchair, rents her own apartment with a nondisabled roommate who provides some support, and drop-in staff for additional support.

The change within the area agency to a focus on individualized supports has meant change for the vendors too. Most have been interested and willing to move in this direction, while a few administrators of vending agencies have left or their contracts have not been renewed with the area agency. As the director put it, "If they're willing to change, I'm willing to work with them to do that."

Over the years, the area agency has acquired some property, and then contracted with vendors to operate the services. Currently, with the change to smaller settings, the area agency has decreased the amount of property it owns, and has a commitment not to purchase any more property. The vendors in the region that own property are doing the same. Staff at the area gency feel they are not in a financial position to dispose of all their property. However, as an alternative, they have pursued alternative uses, such as renting to people without disabilities.

The area agency has begun to actively seek alternative ways of financing home ownership. In order to do so, they hired Beth Raymond, who had 12 years of experience at the Nashua Housing Authority. They have begun making regular use of Section 8, which can be used for people in group homes and then can move with them to an apartment. They foresee a need for continued use of Section 8. As Beth put it, "As people move from group homes to individualized housing, Section 8 is going to have to play a role." Beth has also been making efforts to help people tap into home ownership through low income mortgage programs. She feels that a close working relationships with bankers will be a key to this.

Because of the long waiting lists for residential services, Beth has also been working with families to plan for and create residential options for their sons/daughters on their own, outside of the residential service system. As such, she has encouraged them to: (1) plan for housing; (2) access community resources to help pay for housing and supports; and (3) include others (extended family members, friends, community people) in this planning process.

As an example of this, one family within the Region have become both the case managers and the vendor for their daughter, in order for her to receive supports in her own apartment. The parents, long-time activists in the disability field, did not want their daughter to have to move to a service setting or facility when she moved out of their home. The creation of this opportunity illustrates the capability for flexibility within the system. The

parents are explicit that one of their main purposes in doing so was to see how it would work so that it could become an option for other parents also. There are at least two potential problems with this. One is the idea that families should have to become "vendors" in order to establish this type of supports for a son or daughter. Another is that live-in roommates and support staff are taxed at a much higher rate than they would be if they were designated as "family care providers."

Finally, within Region VI, there has been an effort to reduce the residential service waiting list by targeting mildly disabled people. It is anticipated that, with some of these people, the agency will be able to finding roommates and/or establish other supports relatively quickly. Two possible problems are that (1) some of these people may require much more time and resources than is anticipated; and (2) some people with more severe disabilities may be in greater need for more immediate change.

Quality Assurance

The change which is happening now, within the area agency, is being done based on the quality assurance philosophy and process they have established. This is based on the "five accomplishments," developed by John L'Brien--(1) community presence; (2) protection of rights and promotion of personal interests; (3) competence development; (4) status improvement; and (5) community participation. With these as a guide in evaluation, staff have found that they are best promoted in situations with

individualized residential supports, rather than in group settings. Thus, on this basis, they are pursuing their changeover in types of supports.

In addition, staff training is heavily based on social role valorization (SRV, formerly normalization), developed by Wolfensberger. Area agency staff are required to have 6 hours of SRV training; 5 hours of Effective Teaching training (similar to Gentle Teaching, developed by John McGee); and PASSING (Program Analysis of Services Systems' Implementation of Normalization Goals) training. All vendors' staff are required to have SRV training, which the area agency conduct, or the vendors can do it themselves, with area agency monitoring. In addition, all staff are required to take 5 hours of Effective Teaching training. For behavioral issues, staff in Region VI usually do specific training around a specific person, with emphasis on looking at the communicative functions of people's behaviors. For all behavioral issues, a focus on increasing people's communication and choices is emphasized.

Every residential setting is evaluated by the area agency at least every 2 years. For the typical area agency evaluation, Brenda Gilman, who coordinates quality assurance reviews and staff training, gathers a team of at least five people. This consists of a combination of Area Agency staff, parents, advocates, and other community members. According to Brenda, there is currently "more of a push to get parents on teams than previously." Members of the team attend a training day on SRV and the "five

accomplishments." Then, over a 3-day period, they make numerous visits to the setting at different times of day, including some meals, and so forth. They conduct a group interview of the staff. Staff members may also have individual interviews with team members. After the visits are complete, team members spend a day "conciliating" their findings. Based on this, the team comes up with a list of goals and objectives for the vendor, addressing negative areas. The vendor is responsible for developing an implementation strategy, in consultation with area agency staff. A management team from the area agency meets with them monthly, and Brenda meets with them quarterly to review progress. If corrective steps are not taken, the vendor will receive a written notification of warning. After two warnings, the area agency can pull money based on "default of contract." They have not yet gotten to the point of taking this last step, but have sent letters of warning about doing so.

Two key aspects of quality assurance in Region VI are: (1) its basis in a strong set of values, which guide all phases of the process; and (2) its implementation--that is, the fact that there is follow-up to each review; the result is not just a report that gets covered with dust, but a document to guide change, an expectation that the change will be forthcoming, and consequences if it is not.

Conclusion

There are several strengths of the way that the area agency in Region VI guides, develops, and implements service delivery. There are challenges that lie ahead, as the Region continues to change and support people in individualized ways. And, there are lessons for people who are struggling with both closure and quality of life in the community. Some of these strengths, challenges, and lessons are highlighted here.

While a strength of Region VI is its individualized family supports, one of the challenges lies in embedding these supports within a context of permanency planning for children. This will involve efforts focused on reunification for families whose children are in out-of-home placement, as well as further development of adoptive and foster care options, in order to entirely eliminate placement of children in residential schools or other congregate or segregated facilities. In 1991, approximately 90 children were out-of-district at places such as residential facilities or schools. A major focus of the current 5-year plan is to bring these children back to Region VI.

The efforts toward development of individualized supports for adults is another strength of the area agency in Region VI. As these have been developed, vendors have begun to learn how to listen to people better, how to better assist people to make informed choices, and how to support staff in new roles such as roommates and facilitators of community connections. In this regard, it is perhaps most important that the vendors be encouraged

to take the time to learn from their own experience, that of other vendors within the Region, and others in the state who have had experience in this, in order to avoid repeating some mistakes and share creative ideas and strategies.

Another strength is that the agency has taken a proactive role both in guiding and development of services and in monitoring and evaluating their effectiveness. Area agency staff are in close contact with people served by vendors in the region. Staff do not hesitate to step in to advocate for individuals. And, the area agency as a whole will step in and run direct services temporarily if there is a breakdown within the vendor system. A future challenge will be adapting the quality assurance efforts to a system of services comprised of people's homes rather than group living environments.

A major strength of this area agency is that they are not afraid of change. They have been through many changes over the years, and they continue to evolve. There is an expectation by staff that things change, as well as the flexibility and creativity to do so. As the director put it, "Some people say to us, 'Why not just leave well enough alone.'" She is clear that this is not conceivable once one has seen the possibilities for something better.

They have focused their efforts around change simultaneously on three areas: (1) involvement within the services system; (2) involvement within the community; and (3) involvement within the state political system. Human services do not and cannot operate

in isolation. It is crucial to recognize the connections between the service system, community, and larger political context. By doing so, the efforts of staff in Region VI to further integrate people with disabilities and improve their quality of life have been enhanced.

Finally, the experience of this area agency in their process of change offers important lessons to others doing the same. First, they found that since closure has been completed, they have had more time and resources to invest in improving people's quality of life in the community. However, they also realized that the smaller group homes they were creating were not the same as individualized supports, and were not what people really wanted. As they develop supports today, they are increasing the numbers of people for whom they provide individualized supports. Occasionally, still, there are times when they make trade-offs, for example, moving someone from one of the group homes they still have to another group living arrangement, rather than developing individualized supports for that person. What is important, however, is their recognition now that these are trade-offs, for the short term, and not the kind of supports that they envision for people for the long term.

Today, many agencies across the country are facing the dual challenge of closure and quality of life in the community. Based on the experience of Region VI, it is clear that this involves three things: (1) the willingness to change things that seemed good in the past but today seem either not good, or mediocre at

best; (2) the ability to recognize when one is providing individualized supports, and when, where, and why one is making certain trade-offs or compromises; and (3) when one makes such trade-offs, consciously trying to avoid the establishment of structures that will be inflexible and/or difficult to change in the future (e.g., purpose-built facilities, agency ownership of property).

Region VI's path is one of continual evolution and change, guided by a strong set of values and by listening to people whom they support. They don't claim to have had all the answers in the past, and they don't claim to have all the answers today. Most important, they have a willingness to keep exploring new and better means of supporting people at home in the community.